

General

Title

Adolescent assessment of preparation for transition to adult-focused health care: composite score for the "Transfer Planning" domain on the Adolescent Assessment of Preparation for Transition (ADAPT) Survey.

Source(s)

Center of Excellence for Pediatric Quality Measurement (CEPQM). Measuring the preparation for transition from pediatric-focused to adult-focused health care: the Adolescent Assessment of Preparation for Transition (ADAPT) Survey. Boston (MA): Center of Excellence for Pediatric Quality Measurement (CEPQM), Boston Children's Hospital; 2014 Jul. 34 p. [4 references]

CHIPRA Pediatric Quality Measures Program (PQMP) candidate measure submission form (CPCF): adolescent assessment of preparation for transition (ADAPT) to adult-focused health care. Boston (MA): Center of Excellence for Pediatric Quality Measurement (CEPQM), Boston Children's Hospital; 98 p. [4 references]

Measure Domain

Primary Measure Domain

Clinical Quality Measures: Patient Experience

Secondary Measure Domain

Does not apply to this measure

Brief Abstract

Description

This measure is used to assess the composite score for the "Transfer Planning" domain on the Adolescent Assessment of Preparation for Transition (ADAPT) Survey.

This composite is produced by combining responses to four questions:

Q15: In the last 12 months, did you and this provider talk about whether you may need to change to a new provider who treats mostly adults?

Q16: In the last 12 months, did this provider ask if you had any questions or concerns about changing to a new provider who treats mostly adults?

Q17: In the last 12 months, did you and this provider talk about a specific plan for changing to a new provider who treats mostly adults?

Q18: Did this provider give you this plan in writing?

The ADAPT Survey measures the quality of health care transition preparation for youth with chronic health conditions, based on youth report of whether specific recommended processes of care were received. Responses from a survey sample derived from a clinical program or health plan are summarized in 3 domain-level composite scores. ADAPT composite scores are calculated using the summation of positive responses to between 3 and 5 individual items.

Note: The ADAPT Survey sample is derived from either (a) a primary care or specialty practice in a hospital or community setting (clinical program) or (b) a defined population of covered individuals (e.g., health plan, accountable care organization). A version of the survey was developed for each of these types of samples. These versions differ only in how the patient's physician or other health care provider is identified. The clinical program version should be used if a particular clinician of interest is known (generally the patient's "main provider" for his or her chronic illness). The health plan version can be used to identify the likely "main provider" if claims or billing data are available.

Rationale

The Adolescent Assessment of Preparation for Transition (ADAPT) Survey was developed to serve as a validated, patient-reported instrument to measure transition preparation in youth with chronic health conditions. This tool will enable payers and health care delivery systems to assess provision of key components of transitions preparation and design innovative strategies for improvement, including disease self-management and prescription management education, and planning for the transfer to adult care.

Transition from Pediatric to Adult-focused Health Care: Navigating the Health Care System from Adolescence to Young Adulthood

Health care transition (HCT) has been defined as a planned, purposeful process in which adolescents and young adults to move from pediatric-focused health care delivery to adult-focused delivery (American Academy of Pediatrics [AAP] et al., 2002). The goal of HCT is to maximize lifelong functioning and potential through the provision of uninterrupted, high-quality, developmentally appropriate health care services (AAP et al., 2002). The lack of effective transition from pediatric to adult-focused health care may contribute to fragmentation of health care and increased risk for adverse health outcomes. Those at highest risk during this period include youth with special health care needs (YSHCN) (Lotstein et al., 2005).

The process of HCT involves three key phases: 1) transition planning and preparation; 2) transfer of health care to an adult-focused model; and 3) intake to the adult-focused health system. There is broad consensus that preparation for HCT should start in adolescence and involve individualized planning and ongoing skills development (AAP et al., 2011).

In 2002, a consensus statement from the AAP, the American Academy of Family Physicians, and the American College of Physicians envisioned the goal that by 2010 "all physicians who provide primary or subspecialty care to young people with special health care needs 1) understand the rationale for transition from child-oriented to adult-oriented health care; 2) have the knowledge and skills to facilitate that process; and 3) know if, how, and when transfer of care is indicated" (AAP et al., 2002). For youth receiving care in pediatric-focused health care settings, preparation for HCT includes the acquisition of self-care skills and promotion of increased youth responsibility for chronic condition management. For many youth, transition preparation culminates in a transfer to a new health care setting. However, even for youth who do not change care settings (e.g., those in family medicine settings), the shift to adult-oriented health care still requires appropriate preparation. Because transition preparation is primarily a series of interactions with clinicians, obtaining reports from youth directly about their experience is critical to understanding current gaps in health care delivery for this population.

Rationale for a Youth-reported Measure of Transition Preparation

Because transition preparation must be tailored to adolescents' evolving self-management skills and level

of independence, direct assessment of youth experiences with the health care system is an important means of quality measurement.

Adolescents are best able to judge how well their providers are meeting their needs. Notably, the association between patient-centered care and health outcomes has been shown to be stronger when patient-centeredness is measured by patient report rather than provider or researcher assessment (Stewart et al., 2000; Theunissen et al., 1998). Such assessment is likely to stimulate additional improvements in patient-centered processes and outcomes of care.

Research in adolescents has indicated that youth self-report is reliable in evaluation of health service delivery (Klein et al., 1999; Santelli et al., 2002). Because consensus recommendations for transition preparation identify 14-15 years as the ideal age to initiate the development of a patient-specific transition plan (AAP et al., 2011), querying patients at 16-17 years captures them at a time by which some transition preparation generally should have occurred. A review of 43 transition studies published from 1982 to 2003 found that the most frequently cited age range for ideal transition was between 16 and 22 years old. Only few studies have reported initiation of transition planning at 15 years or younger (Betz, 2004).

Evidence for Rationale

American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group, Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011 Jul;128(1):182-200. [PubMed](#)

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Primary Health Components

Patient experience; health-care transition; transfer planning; adolescents

Denominator Description

For survey items within each composite score, the denominator is the number of respondents for whom the item is scored as 0 or 1.

See the related "Denominator Inclusions/Exclusions" field.

Numerator Description

For survey items within each composite score, the numerator is the number of respondents with a positive response (item score of 1).

See the related "Numerator Inclusions/Exclusions" field.

Evidence Supporting the Measure

Type of Evidence Supporting the Criterion of Quality for the Measure

A formal consensus procedure, involving experts in relevant clinical, methodological, public health and organizational sciences

Focus groups

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Additional Information Supporting Need for the Measure

Relation of Health Care Transition (HCT) to Future Health of Children with Special Health Care Needs

Adolescents and young adults with chronic health care conditions are particularly vulnerable to adverse health outcomes related to prolonged interruptions in health care delivery such as may occur during the periods of HCT (Lotstein et al., 2005). For example, young adults with asthma were less likely to have a primary care visit, less likely to fill a short-acting beta-agonist prescription, and more likely to visit an emergency department compared with adolescents (Chua, Schuster, & McWilliams, 2013). Young adults with diabetes who felt unprepared for transition had an increased likelihood of gaps in care greater than 6 months between pediatric and adult care than those who were more prepared (Garvey et al., 2012). Other data suggest that youth may be transitioning out of pediatric care without appropriate follow-up, skills, or knowledge needed to succeed in an adult-oriented system (Reiss & Gibson, 2002; Rosen, 1995). Measuring the quality of HCT preparation on youth with special health care needs (YSHCN) has great potential to motivate improvements by health care professionals and systems for the patients most likely to benefit. At the same time, approaches to improving HCT preparation for YSHCN could be applied to improve the transition process for all adolescents as they transition to adult-focused care delivery.

Preparation for Health Care Transition: a Quality Gap

Nationally, there is a striking lack of attention to implementing recommendations for HCT outlined in consensus statements and little uniformity in approach even within health care systems. In the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN) a minority of parents reported

having discussed transition with their child's physician (Lotstein et al., 2005), and only 30% had a plan for addressing transition needs (Scal & Ireland, 2005). In the 2005-2006 NS-CSHCN, this percentage remained below 50% (Lotstein et al., 2009). Application of Maternal and Child Health Bureau (MCHB) transition services quality metrics to these parent-reported data revealed variable state-level performance, with an individual state's performance predicted by the proportion of patients with a medical home and adequate health insurance (Kane et al., 2009). Compared to the 2005-2006 survey, no significant improvement in rates of transition preparation was found in the 2009-2010 NS-CSHCN (McManus et al., 2013). In the 2007 Survey of Adolescent Transition and Health (SATH), approximately half of patients aged 19 to 23 years reported receiving counseling around transition (Sawicki et al., 2011). No national surveys have directly assessed transition preparation from the perspective of adolescents themselves. These findings all suggest considerable room for improvement in HCT preparation for YSHCN. However, this potential will be realized only with adequate measurement, benchmarking of performance, and concerted efforts at improving care.

Preparation for Health Care Transition: Lack of Standardized Quality Measurement

In its 2011 Patient-Centered Medical Home Standards, the National Committee on Quality Assurance (NCQA) (2011) included a specific requirement to address care transitions in primary care. The MCHB identified HCT services as a core outcome for the community-based services required for CSHCN under Title V and Healthy People 2000 and reiterated this priority in the Healthy People 2010 and Healthy People 2020 goals (American Academy of Pediatrics [AAP] et al., 2002; Lotstein et al., 2009; McManus et al., 2013). However, systematic assessments of transition readiness are rarely incorporated as part of routine health care (McManus et al., 2013). Measuring the quality of HCT preparation is intended to drive providers to adopt strategies that foster disease self-management among youth and reliably result in safe and effective transfer to adult care (Park, Adams, & Irwin, 2011).

Disparities in HCT Preparation

Socioeconomic, racial and ethnic disparities have been documented in the receipt of HCT services (Lotstein et al., 2010; Richmond, Tran, & Berry, 2011). In the 2005-2006 NS-CSHCN, fewer African-American and Latino respondents reported having discussed shifting their child's care to an adult-focused provider (Lotstein et al., 2010). In the same survey, the proportion of respondents who met the core performance outcomes for successful transition increased significantly with increasing family income (Lotstein et al., 2009). Additionally, the 2007 SATH revealed that low-income young adults had poorer access to health care than those with higher incomes (Lotstein et al., 2010). Such disparities in transition preparation and access to care are likely to result in adverse health outcomes. The Adolescent Assessment of Preparation for Transition (ADAPT) Survey instrument collects data about race and ethnicity to allow for stratified analyses of differences in transition care quality.

Fiscal Burden of Ineffective HCT

Young adults use less ambulatory and preventive care (Fortuna, Robbins, & Halterman, 2009). In 2009, individuals aged 18 to 26 had the lowest health care utilization rates of any age group, and a significant percentage delayed accessing health care due to cost (Lau, Adams, & Irwin, 2013). Many young adults, particularly those with chronic disease and those with public health insurance, also have delayed HCT (Fortuna et al., 2012). Lack of preventive care and timely ambulatory services is associated with increased overall costs as health conditions progress and require higher levels of care (Strickland et al., 2004). Improving transition preparation for at-risk youth may well decrease costs associated with inappropriate or delayed health care utilization.

Evidence for Additional Information Supporting Need for the Measure

American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002 Dec;110(6 Pt 2):1304-6. [PubMed](#)

CHIPRA Pediatric Quality Measures Program (PQMP) candidate measure submission form (CPCF): adolescent assessment of preparation for transition (ADAPT) to adult-focused health care. Boston (MA): Center of Excellence for Pediatric Quality Measurement (CEPQM), Boston Children's Hospital; 98 p. [4 references]

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Reiss J, Gibson R. Health care transition: destinations unknown. *Pediatrics*. 2002 Dec;110(6 Pt 2):1307-14. [PubMed](#)

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Extent of Measure Testing

Reliability

Overview of Survey Development Process

The Adolescent Assessment of Preparation for Transition (ADAPT) Survey was developed to measure the quality of transition preparation by obtaining self-reported experiences of adolescents. The development process included an extensive review of the literature and existing quality measures, interviews with national leaders in health care transition, parent and adolescent focus groups, cognitive testing, pilot testing of the draft survey, a national field test of the survey, psychometric analysis, and composite development.

The Agency for Healthcare Research and Quality (AHRQ) submitted a Federal Register Notice to solicit public comments on potential domains to include in the measure. Input for the measure was included from the literature review, expert interviews, and public comments in response to the Federal Register Notice. To inform survey development, focus groups were conducted to help learn more about experiences with transition preparation in all relevant domains from the perspectives of both parents and adolescents. The final survey was generated through iterative revisions of each item based on cognitive interviews with adolescents and on additional expert input. The final version used in field tests incorporated feedback from all of these sources.

National Field Testing

National field testing was conducted at both the health plan and clinical program levels, because the survey was designed to be used in both of these settings. In all cases, the survey was mailed to the parent or guardian of the identified patient with a cover letter seeking permission for the adolescent patient to participate. This process was developed in response to concerns raised by health plan leaders that sending a survey directly to adolescents (minors) would not be allowed by many plans and hospitals. Parents were asked to provide the questionnaire to the adolescent to complete based on his or her own experience. Each field test used the same mailing protocol. A survey packet containing a cover letter, questionnaire, and postage-paid return envelope was sent to the parent/guardian. After approximately 30 days, a second survey packet was sent to non-respondents. Respondents received an incentive of a gift card worth \$10 for completing the survey.

For the hospital-based clinical program field test, surveys were mailed to 623 Boston Children's Hospital (BCH) outpatients with a wide variety of chronic illnesses receiving care in 10 different clinical programs. This test provided insight into how the survey might be used by hospitals or clinical programs within a subspecialty, or other defined population. A total of 293 surveys were returned (response rate 47%).

For the health plan field tests, two health plans, AmeriHealth Caritas Pennsylvania (AHCP), a Medicaid managed care health plan serving individuals across two regions in Pennsylvania, and Texas Children's Health Plan (TCHP), a pediatric-focused Medicaid health plan serving individuals in Texas, each

distributed 3,000 mailed surveys to their members. Both used the protocol detailed in "Section II: Detailed Measure Specifications" in the original measure documentation. Survey recipients were identified by analysis of health plan claims using the Pediatric Medical Complexity Algorithm (PMCA) (Simon et al., 2014). This publicly available algorithm uses International Classification of Diseases, Ninth Revision, Clinical Modification diagnosis codes in health plan claims to identify youth with either complex chronic disease (C-CD) or noncomplex chronic disease (NC-CD). 1,339 surveys were received (780 from AHCP and 559 from TCHP; response rates 27.5% and 20.7%, respectively).

Respondent characteristics for the three field test samples are presented in Tables 1a-c of the original measure documentation. Female respondents outnumbered males in all three samples. Approximately 40% to 45% of respondents in each sample were 16 years old, with the remaining respondents 17-years old. The samples were diverse in race/ethnicity. Among the BCH respondents, 29% were insured by Medicaid, as were all respondents in the two health plan samples. Of note, all of the samples included individuals with a broad range of self-reported health status; 40% or more of each sample reported their overall health as only good, fair, or poor.

Respondents and non-respondents were generally similar in all three samples. Compared to non-respondents, there was a higher proportion of 17-year-old adolescents in the AHCP respondent sample only ($p < .05$). There were lower proportions of black patients in the respondent samples compared to non-respondents in the BCH sample (5% vs. 12%) and AHCP (24% vs. 35%) (both $p < .01$), but the proportion of Hispanic adolescents among respondents and non-respondents was similar in all three sites.

The ADAPT Survey incorporates quality measures in three domains of health care transition (HCT) preparation: (1) Counseling on Transition Self-Management; (2) Counseling on Prescription Medication; (3) Transfer Planning. The scoring algorithm for these domains is described in "Section II: Detailed Measure Specifications" in the original measure documentation. These domains were designed to capture key areas of transition preparation identified by expert interviews, focus groups, and cognitive interviews (see "Section X: Understandability" in the original measure documentation).

Internal Consistency Reliability

In order to summarize processes associated with the quality of transition preparation, composite measures were developed that incorporate multiple individual survey items. Each composite assesses the extent to which the components of preparation for a specific aspect of health care transition occurred, as reported by the adolescent. The three composite measures included in the ADAPT Survey are: (1) Counseling on Transition Self-Management; (2) Counseling on Prescription Medication; and (3) Transfer Planning. Each composite was designed to measure a single underlying construct of transition preparation. The ordinal alpha provides reliability results for all composites. In general, internal consistency reliability of .7 or greater is desirable. The ordinal alpha is provided for each of the composite measures in each of the three field test sites (see Table 2 in the original measure documentation). All composite measures in all sites had an internal consistency of .7-.8, with the exception of a single composite measure in one site.

Comparison of Responses Across Field Test Sites

Another measure of reliability is the extent to which measure results are reproducible across different care settings that would be expected to have relatively similar care quality. Although the test sites in the field testing varied widely in their geographic location and demographic characteristics, composite scores and responses to individual items were similar across the three field tests. Table 3 in the original measure documentation presents composite scores for each of the three domains by site, and Table 4 in the original measure documentation presents descriptive data on selected individual item responses by site.

Validity

A "gold standard" does not exist for determining the criterion validity of patient-reported measures of quality. However, to ensure the validity of the ADAPT Survey results, rigorous procedures were followed representing best practices within the field to develop the survey. To ensure the content validity of measures of the transition experience from patients' perspectives, qualitative methods were used,

including both focus groups and cognitive interviews, to inform development of the survey items. Quantitative methods were used, including confirmatory factor analysis, internal consistency reliability, item-to-composite correlations, and composite-to-composite correlations to evaluate both the reliability and validity of the final survey. Furthermore, in order for patient-reported measures to provide valid comparisons across health care settings, it is important to use standardized data collection methods and scoring (Goldstein et al., 2005); detailed instructions for these processes are provided in "Section II: Detailed Measure Specifications" in the original measure documentation.

For additional testing information, refer to the original measure documentation.

Evidence for Extent of Measure Testing

CHIPRA Pediatric Quality Measures Program (PQMP) candidate measure submission form (CPCF): adolescent assessment of preparation for transition (ADAPT) to adult-focused health care. Boston (MA): Center of Excellence for Pediatric Quality Measurement (CEPQM), Boston Children's Hospital; 98 p. [4 references]

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State of Use of the Measure

State of Use

Current routine use

Current Use

not defined yet

Application of the Measure in its Current Use

Measurement Setting

Ambulatory/Office-based Care

Transition

Type of Care Coordination

Coordination between providers and patient/caregiver

Professionals Involved in Delivery of Health Services

not defined yet

Least Aggregated Level of Services Delivery Addressed

Clinical Practice or Public Health Sites

Statement of Acceptable Minimum Sample Size

Specified

Target Population Age

Age 16 to 17 years

Target Population Gender

Either male or female

National Strategy for Quality Improvement in Health Care

National Quality Strategy Aim

Better Care

National Quality Strategy Priority

Effective Communication and Care Coordination

Person- and Family-centered Care

Prevention and Treatment of Leading Causes of Mortality

Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Data Collection for the Measure

Case Finding Period

Unspecified

Denominator Sampling Frame

Patients associated with provider

Denominator (Index) Event or Characteristic

Clinical Condition

Encounter

Patient/Individual (Consumer) Characteristic

Denominator Time Window

not defined yet

Denominator Inclusions/Exclusions

Inclusions

For survey items within each composite score, the denominator is the number of respondents for whom the item is scored as 0 or 1.

The Adolescent Assessment of Preparation for Transition (ADAPT) Survey is intended to be completed by youth either (a) receiving health care services in a clinical program or (b) enrolled in a health plan or similar defined population. Eligibility for participation is based on the following criteria:

- Age 16 to 17 years old at the time of survey completion

- At least one chronic health condition

- At least one outpatient visit with a health care provider in the preceding 12 months

- For health plan sampling, current enrollment at the time of the survey and enrollment over the preceding 12 months (allowing for less than or equal to 45 day gaps during that period)

Note: Include patients in the sample frame unless there is positive evidence that they are ineligible or fall within an excluded category. If information is missing on any variable that affects survey eligibility when the sample frame is constructed, do not exclude the patient from the sample frame because of that variable.

Exclusions

- Patients who request that they not be contacted

- Court/law enforcement involved patients (i.e., prisoners); this category does not include those residing in halfway houses

- Patients with a foreign home address (the U.S. territories—American Samoa, Guam, Northern Mariana Islands, Puerto Rico, and Virgin Islands—are not considered foreign addresses and therefore are not excluded)

- Patients who cannot be surveyed because of local, state, or federal regulations

Exclusions/Exceptions

not defined yet

Numerator Inclusions/Exclusions

Inclusions

For survey items within each composite score, the numerator is the number of respondents with a positive response (item score of 1).

Note: The Adolescent Assessment of Preparation for Transition (ADAPT) Survey composite scores are calculated using the summation of positive responses to between 3 and 5 individual items. Complete instructions for composite score calculations are provided in the original measure documentation.

Exclusions

None

Numerator Search Strategy

Fixed time period or point in time

Data Source

Patient/Individual survey

Type of Health State

Does not apply to this measure

Instruments Used and/or Associated with the Measure

Adolescent Assessment of Preparation for Transition (ADAPT) Survey

Health Plan

Clinical Program

Computation of the Measure

Measure Specifies Disaggregation

Does not apply to this measure

Scoring

Composite/Scale

Rate/Proportion

Interpretation of Score

Desired value is a higher score

Allowance for Patient or Population Factors

not defined yet

Standard of Comparison

not defined yet

Identifying Information

Original Title

Adolescent assessment of preparation for transition (ADAPT) to adult-focused health care: transfer planning.

Measure Collection Name

Adolescent Assessment of Preparation for Transition (ADAPT) Survey

Submitter

Center of Excellence for Pediatric Quality Measurement, Boston Children's Hospital - Hospital/Medical Center

Developer

Center of Excellence for Pediatric Quality Measurement, Boston Children's Hospital - Hospital/Medical Center

Funding Source(s)

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Composition of the Group that Developed the Measure

Core Team:

Yuefan Chen, MSc
Jonathan A. Finkelstein, MD, MPH (*Measure Co-Lead*)
Katharine C. Garvey, MD, MPH
J. Lee Hargraves, PhD
Gregory S. Sawicki MD, MPH (*Measure Co-Lead*)
Mark A. Schuster, MD, PhD (*Principal Investigator, Director*)
Sara L. Toomey, MD, MPhil, MPH, MSc (*Managing Director*)
Kathryn A. Williams, MStat

Financial Disclosures/Other Potential Conflicts of Interest

Unspecified

Adaptation

This measure was not adapted from another source.

Date of Most Current Version in NQMC

2014 Jun

Measure Maintenance

Unspecified

Date of Next Anticipated Revision

Unspecified

Measure Status

This is the current release of the measure.

Measure Availability

Source not available electronically.

For more information, contact the Boston Children's Hospital at 300 Longwood Avenue, Boston, MA 02115; Phone: 617-355-6000, or 800-355-7944; Web site: www.childrenshospital.org

NQMC Status

This NQMC measure summary was completed by ECRI Institute on May 25, 2016. The information was not verified by the measure developer.

Copyright Statement

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Production

Source(s)

Center of Excellence for Pediatric Quality Measurement (CEPQM). Measuring the preparation for transition from pediatric-focused to adult-focused health care: the Adolescent Assessment of

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